

## Testimony in support of SB 200

### **An Act Expanding Health Insurance Coverage of Specialized Formula for Individuals with Eosinophilic Disorders**

#### **Insurance and Real Estate Committee**

**March 6, 2014**

Thank you for giving me the opportunity to testify in support of SB 200 to expand coverage of medical food. My name is Conor Landry, I am 12 years old and I live in Fairfield, Connecticut and I attend St. Thomas Aquinas Catholic School. I am in the seventh grade. I have a disease named Eosinophilic Esophagitis or EE. I was diagnosed when I was 7 ½ years old. I will be 13 years old next week. EE is an internal disease in the esophagus in which eosinophils build up and cause clogging in my esophagus. Sometimes, the clogging can be so bad that you can't swallow any foods and need to go on a feeding tube.

I have been treated by doctors in New York City, Cincinnati and now in Greenwich and New Haven. My disease is difficult to diagnose. I don't look sick on the outside but sometimes I am so sick on the inside that the doctors talk about putting me on a feeding tube. I am at the hospital every 3 months to have endoscopies with biopsies. Sometimes I pass the endoscopies and can try a new food and sometimes I fail. When I fail a scope it means the food that I have been trialing has made me sick. This means I have to start over and eliminate another food.

When I was first diagnosed, I was given a special formula to drink called Splash EO28. It was like a juice box. It provided me with necessary ingredients to balance my already limited diet. My little brother, Christopher, also has EE. He has had it since he was born. He is on a different kind of formula that he drinks every day. I am one of the lucky ones – I am sometimes able to control my disease with food but I have a very limited, restricted diet. My doctor re-evaluates my diet every three months. Sometimes I think that it would certainly make my life a little easier if I were on a feeding tube. This way I would know for sure that what I am eating wouldn't be making me sick. Going to parties or even just out for the day with my family can be difficult because I never know what foods will be served. I have to bring whatever food I eat with me wherever I go.

It is a constant possibility that I could go on a feeding tube, I worry about my parents paying for the supplies that I need because I will no longer be covered by insurance. I will be 13 soon and the coverage ends at age 12.

This is something that I don't understand and maybe someone here can explain it to me. If I had diabetes, my medications would be covered. Would you take away my insulin when I turn 13 next week? No, of course, you wouldn't. I don't understand why having EE is any different. Why would I be deprived of what I need?

This is an important time in my life when my body should be growing – if I can't have what I need to help me grow than how can I grow? I know that when I am not in

remission and the disease is active, I have to see more doctors. I have been to the emergency room, stayed overnight trying to manage my disease. Why wouldn't insurance companies want me to have something that would make me healthier? It would keep me away from the emergency room, emergency endoscopies and everything else that I have to go through when I am sick. If I had a broken arm, wouldn't you want to see me in a cast? How is this any different?

If you list my Eosinophilic disorder in the bill and changed the age, it would make it easier for me to get what I need to stay healthy. Please help me get what I need.

Thank you for listening to me,

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